The TurnerFertility study and counselling was designed by the TurnerFertility team in consultation with a board of patients and patient representatives.

In most cases, families were informed of the possibility of OTC by their attending paediatrician, others first heard about the study through a press release. First, families attended one of the informative meetings. On average, these meetings took about 90 minutes. Both parents and daughters were invited. The informative meetings were led by two members of the TurnerFertility team. The first 45 minutes included visual and textual information in layman’s terms about fertility in TS, OTC and alternative options for fertility preservation or future parenthood. The last 45 minutes were used for questions. Between December 2017 and March 2020, seven informative meetings took place.

Second, after referral by the paediatrician, the girl with TS and her parents were invited for a personal consultation of about 60 minutes with a dedicated physician in reproductive medicine or a dedicated gynaecologist with subspecialty reproductive medicine at Radboudumc. Before the consultation, each case was discussed within the ‘dedicated team’ consisting of gynaecologists with subspecialty reproductive medicine, paediatric endocrinologists, paediatric surgeons, paediatric anaesthesiologists, a paediatric psychologist and a PhD candidate who also worked as a physician reproductive medicine. The patient-specific risk profile, which included clinical, hormonal and genetic parameters, was taken into account. This resulted in either a neutral advice (approval) or a restrictive advice (discourage or decline) regarding OTC. The personal consultation included I) room for questions about the informative meeting, II) repeated visual and textual information regarding fertility in TS, OTC and alternative options for fertility preservation or future parenthood, III) physical examination, which included an abdominal ultrasound, blood tests and a buccal smear, and IV) advice regarding the best personal options for future parenthood. The referring paediatrician received a letter with the findings and information about the personal consultation.

Finally, a website including age-specific information and a decision aid was available. Families were made aware of this during the informative meeting. Regarding OTC, there were specific patient-information brochures for parents, for girls under 12 years old, which included only images, and for girls of 12 years and older. The decision aid included a flow chart based on questions, such as whether there is a desire to have children, whether the girl menstruates and whether there are contraindications for pregnancy. The flow chart led to different options for parenthood, which were further explained in an information sheet.

Moreover, families had the option to consult a paediatric psychologist for support during the decision-making process and thereafter.